

**Policy and Funding Subgroup**  
**Prioritization of Top 5 SWOT items, Descriptors and Examples**  
**Brain Injury Services in Iowa**

**Strengths**

- 1. Trauma registry**  
(description of how this works, how it ties into NRF and BISP, how it can be improved and with what policy and funding needed)
- 2. Policy makers requesting input from BI community**  
(this refers to the redesign effort)
- 3. Dedicated state funding stream for BI services (IAC 641Ch. 56)**
- 4. BI included in state Olmstead plan**  
(note BI in state olmstead plan, that advocates have drafted and shared potential for federal complaint to encourage policy and funding alignment with olmstead requirements)
- 5. IDPH Brain Injury Advisory Council**  
(Move to commission)

**Weaknesses**

**1. Length of BI Waiver waiting list and lack of eligibility prescreening:**

As of September 7, there were 620 persons on the BI Waiver waiting list. The next person to be admitted to the waiver will have been waiting 15 months since he/she applied for the waiver. This situation is particularly unacceptable for this disability population because of the need for a continuum of treatment/care from acute care to rehabilitation to community-based services.

Time lost during interim periods of no service can mean a significant decrease in effectiveness of treatment. This is a population with a large number of people whose disability comes on as an adult; they do not have the benefit of 21 years of free special education in the initial phase of their rehabilitation.

The prescreening issue has arisen recently when it was discovered that a number of case managers were using a general functional assessment not specifically applicable for brain injury and thus not suitable for assessing the level and type of services needed.

Policies and Funding Needed: Appropriation to eliminate waiting list; Policy at DHS to fund the full number of slots approved by CMS.

**2. Different BI definitions between registry and services in the Iowa Code:**

(Something about the definition in one is for Acquired Brain Injury and the definition in the other is Traumatic Brain Injury, but I don't know which is which, and I don't know what the effect is.)

**3. Funding cap for BI Waiver, and service selection limited by funding amounts:**

There is a cap on the number of funded slots approved by CMS for the BI Waiver that has been reduced since July from 1,261 to 1,203. The cap on available BI waiver slots based the amount of funding available from DHS has been reduced from 1,168 to 1,337.

In addition, even though there is a \$2,812 cap on monthly funding for BI Waiver services, individual services also have a cap. For example, there is a BI Waiver cap of \$78.88 per month for Supported Community Living for eight or more hours daily by direct care staff.

This is a great hindrance to providers' stepping forward to create and/or provide BI services as they cannot afford to do so at such a low rate, particularly for such services as Supported Community Living or Behavioral Services.

Though the option to seek an Exemption to Policy exists, it is not uniformly known that this option exists nor how to write it up so it will be accepted. This cap for individual services also puts those survivors needing higher cost services at a disadvantage from others and prevents them from selecting the services they need even though those services, by law, are supposed to be available to them. It has been reported to us that currently approved Exemptions to Policy average \$4,000-\$9000 a month, a clear indication that the funding cap listed in policy is too low.

In addition, funding caps on waivers are not uniformly applied across the waiver system.

Policies and Funding Needed: Policy raising the funding cap to a more realistic level; out of date.

#### **4. BI not included in disability services:**

Since the BI Waiver is currently the only funding source for BI community-based services, only those who qualify for the waiver (and are not under the Developmental Disabilities category) are included in Iowa's disability system. The county-based system currently in place has the potential to fund services for other disabilities, mandated in the Iowa Code and existing in State Plans, on a sliding-fee scale, so that not all persons with those disabilities have to spend down to poverty in order to receive funding. That funding comes from state appropriations and/or property taxes.

This situation becomes particularly challenging when a spouse has the injury. The husband or wife, whoever is the caregiver, may have to choose between giving up a job and putting the family into poverty in order to fund the treatment of his/her spouse or giving up a job to care for his/her spouse because there is no other option open.

In 2007, legislation for a four-part Brain Injury Services Program was passed which contained a Cost-Share component. That program is still in Code but has no longer been funded.

Policies and Funding Needed: BI adopted into the Iowa Disability System (formerly Iowa Mental Health System). Legislation appropriating funding for Cost-Share Program.

#### **5. Poverty-based system.**

Because of the BI waiver eligibility requirements, the only way to receive funding for community-based services is to spend down to poverty levels.

Policies and Funding Needed: Include BI in a state-funded system that allows for sliding fee scales. Legislation appropriating funding for the BI Cost-Share Program already in the Code.

### **Opportunities**

#### **1. Neurobehavioral services added to Medicaid**

As a result of advocacy and the identification of more than 40 Iowans being served out of state in programs offering intensive neurobehavioral survive programming (at costs up to and over \$1000/day and > 10 million / year) the Iowa Department of Human Services created a service line using an Exception to Policy (ETP) process that has resulted in one pilot program in the greater Des Moines area providing NB services to 7 individuals. At this time (Fall, 2011) DHS has engaged a workgroup to draft the administrative rules to formally offer Intensive Neurobehavioral Services as part of the Iowa Medicaid Plan. These services are expected to be available in both a small setting residential environment and in the consumers own residence.

Policies and Funding needed: Funding to the repatriation of the more than 30 individuals still out of state as well as funding for hundreds of anticipated eligible individuals.

#### **2. Diversifying revenue sources & dedicating funding**

More than half of the states with BI programming support same via a specific dedicated funding line such as a trust fund or similar mechanism. To date the Iowa legislature has provided funding for a limited set of BI services that has reached its clinical limits with existing funding (NRF and BI training). There is an opportunity to extend best practices to regions of the state not yet well served and the need for planful core funding for core BI services beyond the current Brain Injury Services Program within the IDPH.

Policy and Funding: As part of the BI workgroup recommendations specific guidance on minimum scope of core service and funding must be included.

**3. MHDS redesign—Consistency in provider standards & increased expectations**

As part of the redesign it is anticipated that BI services across the planned regions must be equally accessible, affordable, available, appropriate and acceptable. To achieve this clear minimum standards must be defined for BI providers and the BI services they offer.

Policy and Funding: Clear service definitions and provider qualifications must be defined. Funding for this administrative process must be provided.

**4. Increasing federal \$ draw-down with use of state \$**

Currently the legislature allocates approximately \$450,000 of state funding to the Brain Injury Services Program (NRF and Training) at the IDPH. Some of this money could be utilized to leverage additional federal dollars (the training funds via DHS) to increase the overall dollars available. This is dependent on the continued availability of federal funds.

Policy and Funding: To achieve this ability to leverage additional dollars some diversion of funds from IDPH to DHS must occur via a policy shift or via a MOA between the departments.

**5. Regional TBI teams**

It is anticipated that there is an opportunity to form core “go to” brain injury teams in each of the expected disability service regions. These teams could be provided specialty training in BI service delivery, navigation, accommodation, family systems dynamics and best practices.

Funding and Policy: Core dollars must be allocated for time, training, materials and continuing education for the TBI teams.

**Threats**

**1. Intra-agency fragmentation at the state level—leadership changes can result in programs taking new directions**

This threat refers to the siloing of efforts across programs and agencies such as aging, education, corrections, etc.

Policy and Funding: The ACBI could be raised to a Commission level and the language of appointees could be modified to include cabinet level appointees for increased visibility, capacity and clout.

**2. Lack of BI infrastructure in state & federal government**

This threat refers to the minimal state of BI structure in government at this time. While there are pockets of expertise and interest BI is not woven in and through the range of programs that would best optimize awareness and service delivery.

Policy and Funding: See above for state level option.

**3. One-time fix vs. on-going evolution with CQI**

This threat refers to a historical experience of “redesign” efforts being short term fixes vs. long term capacity building efforts to achieve genuine systems change. The need for the deployment of a phased and sequential array of BI services, embedded in a process of continual quality assessment and improvement is a clear policy and funding mandate.

**4. Competition for limited funding**

BI services will cost money. Additional revenue will need to be identified and deployed for success in this effort.

**5. Downsizing government and government services**

This threat refers to a perception that in the fall of 2011 there is a political atmosphere (at least in Iowa) of probable reduction in Govt. spending and Governmental services. This is a threat as BI services (and disability services en toto) are dependent on government revenue collection, deployment, and evaluation.